

TO: Chair Shane Pendergrass
AT: Maryland State House of Delegates
RE: Support of MD H.B. 109
SPONSOR: Delegate Emily Shetty

FROM: Claudia Fennell, Patient Parent (Batten Disease, CLN2)
DATE: January 19, 2022

Dear Members of the Maryland House of Delegates,

My name is Claudia Fennell, parent to an 8-year-old girl with a rare, neurodegenerative, genetic disorder called Batten Disease type CLN2. Our family is located in Bethesda, Maryland, and I'm here to express my urgent support for **House Bill 109, the "System for Newborn Screening - Requirements,"** aimed to align Maryland's Department of Health newborn screening program with the federal Recommended Uniform Screening Panel (RUSP) recommendations - to ensure that, when a condition is adopted to the U.S. RUSP, Maryland families will then experience the life-saving benefits of timely diagnosis. I support this bill because diagnosis at birth has the ability to completely transform the lives of Batten Disease families.

Penelope was a healthy child, completely asymptomatic, until she was 3 years old. She played and joked with her two siblings and ten cousins, loved scoring soccer goals and playing in the mud. Then, suddenly, she developed intractable seizures, lost her ability to walk, most of her ability to speak, and could barely eat. It was extremely difficult to find a diagnosis, delaying treatment when every week counted. But, eventually we had answers, and she started an enzyme replacement therapy which dramatically slows the progression of her disorder. Untreated, she would have almost certainly passed away by now, and *earlier* treatment could have completely changed the course of the disease.

The effects of Penelope's delayed diagnosis permeate every aspect of our lives. The complexity of her care, and irregularity of her health status means that I am unable to return to the workforce and limits, among other things, our ability to contribute volunteer hours in our community. Our story is not unique among rare pediatric disorders - consider, if you will, the aggregate impact of delayed diagnosis on Maryland families; it is sure to be enormous.

I urge you to support **House Bill 109, the System for Newborn Screening - Requirements** in order to allow families timely access to critical advances in treatment, and reduce the financial impact of illness on families. Thank you for your time today.

Regards,
Claudia Fennell